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Service user involvement in global mental health: What have we learned from recent research in low- and middle-income countries?

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Abstract

Purpose of Review

The *Lancet* Commission on global mental health and sustainable development claims the field of global mental health is undergoing a “transformational shift” toward an ethic of “nothing about us without us”. Yet a systematic review published in 2016 identified few examples of meaningful participation by service users in mental health systems strengthening in low- and middle-income countries (LMICs). To investigate whether this is still the case, we conducted a rapid review of primary research published between June 2017 and December 2018.

Recent Findings

We identified 10 studies reporting on user involvement in LMICs, including three in mental health policy and planning, three in mental health services or capacity-building, and three in treatment decision-making. An additional study was identified as having involved users in data collection, although this was unclear from the original text. Included studies were mostly qualitative and conducted as part of a situation analysis, pilot study or other formative research. Few reported the results of efforts to improve involvement, suggesting this shift remains at an early stage.

Summary

While the number of studies published on user involvement is rapidly increasing, the potentially “transformational” effects of this shift in global mental health are not yet being felt by most users in LMICs.

Key Words

global mental health, user involvement, psychosocial disabilities, disability rights

Introduction

The 2018 *Lancet* Commission report on global mental health and sustainable development identifies four “transformational shifts” in the history of global mental health to-date. Commissioners describe the fourth shift, dubbed “nothing about us without us”, as a “fundamental, rights-based component of the ethos of mental health-care provision and research” (pp.1557).¹ They cite as evidence of this shift a study on the involvement of service usersⁱ in mental health system strengthening in Nepal.²

Yet the field of global mental health has also come under scrutiny for a relative lack of involvement of people with lived experience of mental health conditions in low- and middle-income countries (LMICs), compared to efforts made in high-income countries—which are already deemed insufficient by many critics. Indeed, the United Kingdom’s Global Ministerial Mental Health Summit, where the *Lancet* Commission was officially launched in October 2018, drew criticism for failing to meaningfully engage a wide enough range of user representatives, particularly at early stages of planning:

While a few networks were approached to provide ‘experts by experiences’ to attend panels on themes already decided on, there has been no meaningful consultation or involvement of user-led and disabled people’s organisations not already signed up to the ‘Movement for Global Mental Health’ agenda or funding to enable a wide range of representatives to attend (National Survivor User Network [NSUN], 2018, “Global Ministerial Mental Health Summit- Open Letters”, para. 3).³

This apparent contradiction—between the “transformational shift” described by Commissioners¹ and the observations of advocates at the report’s launch³—led us to question to what extent the principle of “nothing about us without us” is reflected in the literature on mental health in LMICs.

A systematic review published in 2016 as part of the Emerald (Emerging mental health systems in LMICs) programme identified twenty papers reporting on experiences of involving service users and caregivers in mental health systems strengthening in LMICs.⁴ None of the papers was more than ten years old at the time, suggesting that user and caregiver involvement in global mental health is an area of recent and growing interest. However, most papers reported on the involvement of service users and caregivers as research subjects participating in the evaluation of services, not as direct participants in policy or service development, delivery of services or training of service providers, or the actual conduct of research.

To investigate whether this is still the case, we conducted a rapid review of the academic literature published between June 2017 and December 2018, applying search terms from Emerald’s 2016 review⁴ across eight electronic databases: Medline, Embase, PsycINFO, Web of Science, LILACS, SciELO, Global Health and the Cochrane Database of Systematic Reviews [see Web Appendix 1 for search terms]. We included primary research conducted in LMICs using any kind of study design, so long as it reported on the involvement of people with mental, neurological or substance use conditions in mental health policy, services or research [Figure 1]. We excluded editorials, systematic reviews and other secondary research. As this was a rapid review conducted by researchers in English-speaking countries, we were unable to consider non-English texts. Titles, abstracts and full-texts were reviewed by a single screener, who was also responsible for data extraction [See Web Appendix 2 for data extraction table].

Figure 1: Flow Chart for Rapid Review

ⁱAlthough we are aware of the many critiques of the term “service user”, we have chosen to employ it for the purposes of this review, as it was the term most commonly used in the texts under discussion.

[Insert Figure]

Our rapid review returned 10 studies from nine countries across Asia (China,⁵ India,⁶⁻⁸ Malaysia,⁹ Nepal^{6, 10, 11}), Africa (Ethiopia,^{6, 11-13} Nigeria,^{6, 11} South Africa,⁶ Uganda⁶) and Europe (Lithuania¹⁴). The majority of included studies were qualitative and conducted as part of a situation analysis, pilot study or other formative research. Three reported on user involvement in mental health policy and planning,^{6, 11, 12} three on user involvement in mental health services or capacity-building of service providers,^{5, 7, 10} and three on user involvement in treatment decisions.^{9, 13, 14} Upon further consultation with the corresponding author, an additional study was identified as having involved users in data collection.⁸

Involvement in Mental Health Policy and Planning

The Emerald consortium conducted research in six LMICs (Ethiopia, India, Nepal, Nigeria, South Africa, Uganda) and has recently published country-specific¹² and cross-country^{6, 11} qualitative studies reporting on the state of user and caregiver involvement in mental health system strengthening. These studies generally report little to no involvement of users in national, regional or district-level mental health policy or planning. Petersen, Marais, Abdulmalik et al. (2017) indicate that user involvement may be more advanced in India but provide no further details: “With the exception of India, a lack of service user participation was identified across all six countries, with the general uncertainty on how to engage service users” (pp.704).⁶ Lempp, Abayneh, Gurung et al. (2017) conclude that although many stakeholders in Ethiopia, Nepal and Nigeria recognise its importance, user involvement remains extremely limited and often appears tokenistic.¹¹ In Ethiopia specifically, Hanlon, Eshetu, Alemayehu et al. (2017) report that district health officials and heads of mental health facilities are more receptive to the idea of user involvement in less strategic activities, such as awareness-raising and service development, than in policy or planning.¹²

Involvement in Mental Health Services and Capacity-Building

In keeping with Hanlon, Eshetu, Alemayehu et al.’s (2017) observations,¹² our review identified more examples of user involvement in mental health services than in policy or planning. Two studies evaluate mental health programmes involving self-help groups (India)⁷ and formal peer support (China).⁵ Researchers are also piloting a training module on mental health stigma co-facilitated by service users and delivered to primary care workers (Nepal).¹⁰

Mathias, Mathias, Goicolea and Kermode (2017) present a case study of the Burans mental health project in India, which aims to improve community mental health competence through a variety of community-level interventions, including self-help groups for users and caregivers.⁷ Participants report benefits of self-help groups, such as improved social inclusion, though outcomes are not assessed quantitatively. However, self-help groups are widely used in LMICs and their effectiveness has already been investigated in previous studies, including in India.¹⁵⁻¹⁷

Fan, Ma, Ma et al. (2018) describe a rather more innovative peer support programme in China, in which users are recruited as peer providers.⁵ These peer providers lead group sessions with service users focused on developing key skills (daily life skills, social skills, fine motor skills), promoting emotional well-being (emotional support, self-image), and providing health education (mental health literacy, healthy lifestyle) as well as entertainment. Peer providers are recruited, trained and supervised by mental health care providers, and sessions are held in community-based health facilities such as rehabilitation centres and health centres. This is one of very few examples of formal peer support being delivered in a LMIC, and we believe Fan, Ma, Ma et al. (2018) represents the first evaluation of formal peer support in a LMIC to report any quantitative, user-level outcomes.

However, there are many limitations to the study design that call into question its overall positive assessment of the programme. For example, outcomes are self-reported at a single time-point, with no comparison group, in response to a series of yes/no questions that leave little room for nuance in participants' responses. More rigorous evaluation is needed.

Rai, Gurung, Kaiser et al. (2018) appear to be setting the foundation for a robust, cluster-randomised controlled trial of a user co-facilitated training to be delivered alongside other mental health Gap Action Programme training modules in Nepal as part of the RESHAPE pilot study.¹⁰ RESHAPE uses participatory research methods such as PhotoVoice, which helps participants shape a personal narrative through photography, to address stigmatising attitudes of care providers.¹⁸ Much like Souraya, Hanlon and Asher (2018) in Ethiopia,¹³ Rai, Gurung, Kaiser et al. (2018) focus on the roles of caregivers in facilitating users' involvement in RESHAPE. They conclude that caregiver involvement should be adopted as best practice in the conduct of any anti-stigma interventions involving users in this setting.

Involvement in Treatment Decisions

Three qualitative studies (Malaysia,⁹ Ethiopia¹³ and Lithuania¹⁴) report on user involvement in decision-making regarding their treatment. All three studies describe hierarchical relationships between service providers and users in which providers' expert opinions generally prevail. These studies recommend providing more accessible information on treatment options to improve user involvement in decision-making.

In Malaysia, Zaini, Bharathy, Sulaiman et al. (2018) report on formative research informing the development of a tool for shared decision-making in the treatment of major depression.⁹ The authors suggest Malaysia may be in a process of transition "from a traditional 'paternalistic' model of clinical decision making into a current 'informed' decision making model" (pp.9)—a transition which can be better supported by creating standardised tools and procedures for clinicians to follow. However, they note that patients still value clinicians' experience and are less interested in evidence of efficacy from the scientific literature than in examples of cases seen by the clinician previously.

In Ethiopia, Souraya, Hanlon and Asher (2018) investigate the roles of users and caregivers in making treatment decisions in the context of a pilot community-based rehabilitation programme for schizophrenia.¹³ They describe a prevailing culture of collectivist decision-making that results in caregivers often taking responsibility for treatment decisions. Users' roles in decision-making are limited and may also be mediated by social and economic factors, such as gender and poverty. The study concludes that community-based rehabilitation workers can promote user involvement, for example by providing information about treatment options, listening to users' needs and showing respect for their opinions—essentially mediating between users, caregivers and providers, while remaining sensitive to users' autonomy. However, the authors also observe that systems-level resource limitations affect the affordability and availability of different treatment options, and thereby constrain user decision-making.

This point is further illustrated by Sumskiene, Petruzyte and Klimaite's (2018) evaluation of Lithuania's mental health system.¹⁴ In Lithuania, a scarcity of human resources for mental health has translated into a predominantly biomedical approach to care. Psychotherapy is rarely available and therefore not presented as a treatment option. Those who can afford it may turn to the private sector for psychotherapy. Those who cannot must make do with medication alone. The authors posit that overreliance on medication contributes to the "passive position of the patient", due in part to the potentially debilitating effects of overmedication. They also suggest that psychotherapy requires

the user to take a more active role in the treatment process. In this context, the limited number of treatment options available not only diminishes the user's opportunity to exercise choice, but also reinforces the user's "passive position".

Involvement in Research

None of the studies included in this review clearly reported involvement of service users in any capacity other than as research subjects. Three of eleven data collectors involved in a survey on psychosocial disabilities and barriers to participation in North India were identified as people with disabilities.⁸ In personal correspondence, the lead author confirmed that some of these data collectors had psychosocial disabilities, although this was not apparent from the study text.

What does recent research tell us?

For many years, the field of global mental health has focused on narrowing the "treatment gap" in LMICs as one of its central concerns.¹ While studies from Ethiopia, Nepal and Nigeria mention improving access to affordable treatment as an important strategy to help lift barriers to involvement,¹¹⁻¹³ the case of Lithuania reminds us that the kind of treatment matters.¹⁴ Overmedication and potentially debilitating side effects of some psychotropic drugs can impede meaningful participation.

Providing a wider variety of treatment options, including non-pharmaceutical options, and more information about these options— for example by using a shared decision-making tool, as in Malaysia,⁹ or engaging community-based rehabilitation workers in treatment planning, as in Ethiopia¹³—may be steps in the right direction. However, these interventions are still at the early stages of development and piloting; their effectiveness in improving involvement in decision-making has not yet been demonstrated.

Psychosocial interventions like self-help groups in India⁷ and peer support in China⁵ can help empower users to take charge of their own recovery while supporting others. These interventions can also become conduits into higher-level advocacy and involvement in policy and planning. Several of the authors of this review (EN, GR, RM) have witnessed peer support workers and Recovery College trainers in Uganda go on to successfully challenge discriminatory legislation and advocate for more humane and dignified treatment of service users. For example, laws that previously referred to users in Uganda as "idiots, imbeciles and lunatics" have adopted the term "people with psychosocial disabilities" in line with the United Nations Convention on the Rights of Persons with Disabilities.¹⁹⁻²¹

However, Rai, Gurung, Kaiser et al. (2018) and Souraya, Hanlon and Asher (2018) recognise that users' power to effect change can also be curbed by unsupportive caregivers and healthcare providers.^{10, 13} In Nepal, the RESHAPE trial will test whether user involvement in training could be an answer to widespread stigmatization by providers, while making a concerted effort to engage caregivers in the process.

Finally, while there is evidence that cultural factors—such as gender roles and collectivist approaches to decision-making—can weigh on user involvement, most of the studies included in this review highlight the importance of resource limitations as crucial barriers to meaningful participation. What does shared decision-making really mean in a community where there are virtually no affordable treatment options available? What can a user advocacy group be expected to achieve in terms of policy change, if its members cannot afford the time or transport costs to attend a meeting? In low-income countries especially, where the median mental health expenditure is just

\$0.02 USD per person per annum,²² new funding is needed to tackle these sorts of barriers, or we will not see change.¹¹

Conclusion

Over the past 18 months, researchers have asked challenging questions about the current state of user involvement in LMICs. In some cases, they are already developing and testing new strategies to improve user involvement in LMICs in future.^{5, 7, 9, 10, 13} Yet few results have been published, and none of this research appears to be user-led. Only rarely does it actively engage users in any research capacity other than as research subjects. The one exception we note is in India, where a very small number of data collectors with disabilities may have had psychosocial disabilities, though this could not be verified from the text.⁸

Our aim in this review was to investigate whether the purported “transformative shift” in global mental health toward an ethic of “nothing about us without us” represents rhetoric or reality,¹ by drawing on the recent literature. We conclude that this field is at the early stages of such a shift, as evidenced by the rapidly increasing number of studies being published on user involvement in LMICs. However, the potentially transformative effects of this shift are not yet being felt by most users in LMICs. If the field of global mental health is going to make the principle of “nothing about us without us” a fundamental component of its ethos, then this principle must be extended to calls to governments and other funders to increase the resources available for mental health in LMICs.

Key points

- Although the number of studies published on mental health service user involvement in LMICs appears to be growing, much of this is formative research.
- Few recent studies report results of efforts to improve mental health service user involvement in LMICs.
- Mental health service users in LMICs are rarely involved in research in any capacity other than as research subjects.
- Resource limitations are important barriers to mental health service user involvement in LMICs which must be addressed.

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Conflicts of interest

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